

*Patterns of Expenditure*

### 3 Patterns of expenditure

#### **What people thought the attendance allowance was for**

It has never been clearly stated what the attendance allowance is for. It is awarded on the basis of a medical assessment of the extent to which claimants need frequent attention in connection with their bodily functions, *or* require supervision to avoid substantial danger to themselves or others.

- Both the name, and the basis for assessment, might imply that the benefit is intended in one way or another to help meet the costs of the care which is the defining criterion. This would make the ‘attendance’ allowance directly analogous to the ‘mobility’ allowance: the latter is unambiguously aimed at helping people who cannot walk, to pay for alternative means of transport.
- An alternative interpretation is that the attendance allowance is intended more generally to contribute to the whole range of additional costs associated with disability, including heating, laundry, food and so on. According to this hypothesis the attendance criterion is simply a way of identifying people whose disability is serious, and likely to cause such extra costs.

Whatever the general intention, there is no doubt at all that claimants are entitled to spend the money as they choose, without any suggestion that they ‘ought’ to be spending it on approved purposes.

But it is still relevant to ask what claimants thought the purpose of the benefit was, as well as what use they themselves put it to. Most disabled people or their carers did not have a fixed concept of the purpose of the benefit: they had not been told what to spend it on, so they had to guess. Many of them agreed with each suggestion that was

made to them. Others threw the dilemma straight back at us by saying that it was for either purpose:

*It's for people who need attendance ... For people to come in to get them washed and dressed ... And for the additional expenses.*

Four strands of thought could nevertheless be identified among people's responses to this question:

Paying for care:     to pay for outside carers,  
                              to support kin carers;  
Extra expenses:     to cover additional basic costs;  
                              to allow for 'little extras'.

The first view was that the allowance was intended to be spent on cash payments to people – presumably non-relatives – who would come in to provide care. That was the clearest link between money and 'attendance'.

An example of that position was provided by the wheelchair-bound husband of a woman who was receiving attendance allowance: he said that he did not receive the allowance because he did not have an (outside) carer, whereas his wife did. He had, in fact, applied in the past, and been turned down. But other potential claimants may have failed to claim their entitlement because of a similar misunderstanding of the word 'attendance'. [Indeed, a personal acquaintance of one of the authors cared for her aged mother for ten years, but claimed the attendance allowance only in the final months when an agency nurse was hired to do night duty.]

On the other hand, several people commented that the amount of the benefit was far too small to pay for the level of attendance on which the assessment was based.

*It's to make your life easier by being able to pay for extra help.  
But it doesn't work out like that, because to pay for help, where  
are you going to get anyone who will accept £30 a week?  
(Wheelchair-bound woman living alone.)*

The other view of the 'paying for care' version of the allowance's objectives was that it was aimed at the kin carers. Some saw this in general terms...

*It's to pay me to attend to her -- when she wants anything, to get it for her.*

Others made a direct comparison between the attendance allowance paid in support of a kin carer and the much higher costs of institutional care...

*It's cheaper than being in hospital. That's the chief reason they give it, isn't it? (Husband of frail elderly woman.)*

*It's to help you look after the disabled person. But they can't pay me to look after Jane. No way. Because it's a full-time job ... If she was in a home, it would cost £250 a week. (Mother of mentally handicapped girl.)*

But there were several forthright comments on the level of the benefit in comparison with the wages which a carer might have foregone. One respondent was outraged at the suggestion that attendance allowance could be seen in this way:

*I think if you put it like that, that is a bloody cheek!*

Those who saw the allowance in terms of an addition to basic spending money also saw it in two ways.

- Some specifically mentioned the extra necessities like heating and laundry which had to be bought by, or on behalf of, the disabled person.
- Others saw the the money as going towards 'little extras' which might make life more tolerable in spite of the discomfort and inactivity suffered by people who could not take part in 'normal' activities. People commented that the attendance allowance 'sort of bucks up your income', provides a few 'comforts' or 'a bit of icing on the cake'.

For those members of our sample who were living on the margins of poverty, attendance allowance was a vital part of the family budget.

One elderly disabled man said that, without the attendance allowance, 'It'd be murder ... we wouldn't be able to manage'. If his allowance was stopped, he said, then he would have to get rid of his television which he relied on 'to keep me occupied ... Otherwise I'd be looking at the four walls all day.'

The 'little extras' approach seemed to be associated with a better basic balance between income and needs. As one carer said, even without the allowance, her disabled mother 'would have still had (her extras). I'd have seen to that'. Another respondent illustrated the contrast more directly:

The widowed mother of a mentally handicapped girl said that the attendance allowance helped to pay for their car, without which she would have been unable to take her daughter to evening classes or to social events run by the local branch of Mencap. She was expecting to retire from her part-time job soon and added:

*At the moment (the attendance allowance is) an added extra, but it will be essential when I don't go to work.*

Most of the carers drew the attendance allowance from the Post Office on behalf of the person they cared for. Some commented that it made no sense to pay the allowance to the disabled person, since they were often physically unable to collect it. Some of those who felt that the allowance should essentially be a payment for care, also wondered whether it should not be paid to the carer:

*It should really be for my husband, shouldn't it? ... I suppose it's got to be made payable to me or else there could be a swizzle. (Disabled woman cared for by husband.)*

When asked about how they actually used the attendance allowance, or what difference it had made to their circumstances, a few were able to mention a direct link between the benefit and payments for care, as described later. But most disabled people and their carers said that they used the attendance allowance to supplement their household budget. Most households drew the attendance allowance weekly, or every few weeks, and used the money on shopping and everyday expenses. This was in contrast to the way some of them used other sources of income, such as mobility allowance (which was often allocated specifically to the costs of transport) or occupational pensions (which some people tried to save to meet large bills, or as a cushion for use in emergencies).

Some carers wanted to make the point that all the money was spent on the disabled person to whom the allowance was paid.

The mother of a mentally handicapped young man said that she often left her son's allowance in the Post Office for a few weeks, then drew it out to buy him some new clothes that he needed.

The mother of a mentally handicapped woman said that she paid part of the attendance allowance towards an insurance policy for her daughter so that 'if something happens to me, maybe someone will use it to look after her'.

One good way of discussing the impact of the attendance allowance was to ask how people would be affected if they did not have it. For two members of the sample, that was all too real a prospect – their allowance had been cancelled. They were actively contemplating the economies they would need to make.

Mrs Halliday suffers from a painful condition affecting the nervous system which means that she can walk only for short distances, with the aid of a stick. She and her husband live in what they describe as a ‘rough’ council block, and have no car. Because Mrs Halliday cannot use public transport, she rarely goes out. She passes the time by knitting and reading magazines. They save up her mobility allowance and rent a car twice a year for a short holiday with a relative who lives by the sea. At Christmas they treat themselves by renting a video so that they can watch some films.

Now that the attendance allowance is being stopped, Mrs Halliday said:

*It means that I won't be able to save all my mobility allowance. So that will cut down the outings in the summer ... (At the moment) I buy a bit of wool to knit and that to pass my time away – I shall have to stop that ... There won't be a video, not this year. Those little extras, they give you a few little pleasures. When you don't go out much you want something don't you?*

### **Standards of living**

Most people with disabilities and their carers said that they had to manage their money carefully to make ends meet. In some households, money worries were so severe that the problems caused by disability almost seemed minor in comparison:

Mr and Mrs Margolis were the couple in their fifties, both disabled, who were looked after by their two daughters working as a team. The household income consisted of Mr Margolis's invalidity benefit (£73), Mrs Margolis's higher rate attendance allowance and mobility allowance (total £56 a week) and the earnings of the son-in-law who lived with the couple (less than £100 a week). The daughter who lived nearby claimed income support.

The daughters said that the family's main problem was the maintenance and upkeep of their terraced house, which was damp and in poor repair. There were two mortgages – the

second one having been taken out to try to tackle the damp. Mrs Margolis's condition tended to deteriorate in cold weather, yet the system of heating by electric fires was inefficient and expensive: the annual cost of gas and electricity was around £800.

The daughters said that they could not afford the warm clothing that Mrs Margolis needed – woollen tights, slippers, jumpers and warm dresses and nightdresses. They did not have a car, and so Mrs Margolis rarely went out. One daughter described their difficulties as follows:

*The main thing is the money problem ... It weighs me down ... Sometimes I feel really low, you know. It breaks me down ... because I need to get (my mother) things and ... I need the money for myself.*

Mrs Margolis's case was not an isolated one. Other disabled people and their carers spoke about having rent arrears or fuel debts to pay. Asked whether they managed to save anything out of their weekly income, many people indicated that the very idea was unthinkable: 'you must be joking!'

One cold afternoon, the interviewer called to talk to an elderly disabled woman, Mrs Patel, and the husband who cared for her. She found the couple in bed, trying to keep warm. It turned out to be Mr Patel's eightieth birthday! The interview was carried out by the warmth of a one-bar electric fire in the sitting room. Mr Patel said that their joint weekly income was only £69. Fortunately he had some savings which he was using to 'take advantage' of the Government's 'selling off everything' by buying shares which had quickly increased their value. The high point of Mr Patel's day was to spend part of the morning in the local library, reading the newspapers he could not afford to buy. He complained about the price of rice and said that 'Since I retired (12 years ago) I've not bought a single piece of clothing. I can't afford it.'

The people with disabilities and their carers were asked what kinds of things they could not afford, or what they would buy if they received a sudden windfall. In many cases the things they said they needed were all directly related to the physical needs of the disabled person: better heating, more clothes or bedding, an electric wheelchair to help them get about, a microwave to make it easier for a person in a wheelchair to cook for themselves. Many disabled people spent most of their time in their own home, and said that they would love a car so

that they could get out more. A large number said that they had not had a holiday recently; others said that they used to go on council-subsidised holidays, but that these had been cut recently.

At the opposite end of the scale, of course, some people with disabilities lived in comfortable households with the financial means to overcome many of the practical problems caused by the disability.

One retired couple had done everything possible to limit the restrictions the husband's stroke and confinement to a wheelchair had put on their lives. The garden had been turned into a patio, to reduce the amount of work, and Mr Goodwin paid a physiotherapist to help him with exercises on two mornings a week. The couple went out to the local park together every day and had two or three short holidays a year. In the past, their hobby had been amateur dramatics, and from time to time they took a taxi to the theatre eight miles away to see a play.

As the Goodwins' case indicates, those with adequate incomes spent a fair proportion of their money on things which they needed only because of their disability, or which cost extra because they could not do things 'normally'. Other costs incurred by people with adequate resources included adaptations to their home (building an extension or a downstairs toilet), and holidays (paying for an escort to accompany the disabled person, for example).

It has to be assumed that these better-off households' consumption of other goods and services was reduced, compared with what they would have been able to buy if they had no disability. If so they suffered a financial loss, even though they were not necessarily poor.

For the worse-off members of the sample, on the other hand, the need to spend extra on particular items because they were disabled might reduce their standard of living to a very low level. The OPCS survey attempted to measure the extra costs of disability<sup>1</sup>. It suggested that average additional expenditure averaged about £11 per week for people with very severe disabilities, though the figure rose to more than £15 per week for those who were better-off. The OPCS findings have been challenged by the Disablement Income Group, whose own enquiry suggested additional costs more like £70 per week.<sup>2</sup> For our own research, respondents were simply asked to describe their expenditure in general terms, so that we could compare that with other uses of their income.

The extent of these additional costs varied according to the particular circumstances. No one said they had none; several reported extra costs which were substantial, or would have been if the resources had been available to spend. Sometimes costs were ‘out of control’ because the person with the disability was not capable of limiting them.

*The heating bill is astronomical – £180 a quarter. She doesn’t understand how to get into bed to keep herself warm. She just wanders, crying, at night, so you’ve got to keep it heated ... Things go missing, including money ... One day she decided to cut the net curtains in half. (Daughter of woman suffering from dementia.)*

Another general effect of disability on household economies was the reluctance of carers to impose a cheese-paring regime on a loved-one who had such a bad time anyway. They might have been prepared to budget more strictly for themselves, but not for their disabled dependant.

The attendance allowance represented a substantial proportion of the income of people who lived largely on social security benefits. Of course, all the people in this sample were receiving the allowance, so we have no direct evidence about how they would have spent their money without it. But on the basis of the accounts we were given, one answer to the question about what the attendance allowance was used for is ‘basic living expenses’:

- For the poorest, it was having to be spent on the absolute basics that anyone else with a restricted income would be worrying about: food, fuel, clothes and so on.
- For people whose budget was better balanced, it was still going on basics, but could stretch to cover some of the extra basic costs imposed by disability: food, fuel, clothes and so on.
- People with a higher standard living were able to spend some money on items which made living with disability more tolerable. But it could still be argued that it was the allowance which allowed them to do that without eating into the income needed to pay for the same basics – food, fuel, clothes and so on – as everyone else was worried about.

### **Direct payments for care**

Chapter 1 identified four members of the main sample who made payments towards their primary care arrangements. Two of these payments were made to organisations which existed to provide care and support for people with disabilities.

Mrs Wright paid over her attendance allowance – £32.95 per week – to the housing association which provided 34 hours of care through the staff of the neighbouring residential home. The fee was determined by the amount of her allowance, rather than by the actual cost of the care, which must have been subsidised by the charity which ran the home.

Ms Darley paid only £10 per week for her local authority services: a total of 26 hours from a weekday care attendant, a weekend nurse and a home help. The fee was determined by the fact that she was on income support, and was therefore unconnected with the theoretical availability of the attendance allowance.

Both Mrs Wright and Ms Darley received income support and depended entirely on state benefits for their income. Both had quite high incomes by income support standards, receiving mobility allowance as well as the higher rate attendance allowance, while their housing costs were covered by rent rebates. But in both of these cases where formal charges were being levied by organisations (albeit at heavily subsidised rates) all the resources involved in the transfer came from the state system.

Two other 'ordinary' claimants were paying for primary care which they had arranged privately. In both cases, the recipient of the money was already closely tied to the disabled person beforehand.

Mrs Paxton received 30 hours of care a week from her daughter-in-law, to whom she paid £30 per week. This figure was probably arrived at as an approximation to her attendance allowance of £32.95. At £1 an hour, the daughter-in-law's pay was well below the market rate.

Mrs Paxton said that, although her daughter-in-law had been reluctant to accept payment, she felt obliged to pay for the care she received:

*I've got to pay my daughter-in-law ... I can't expect her to do something for nothing ... She didn't want any payment (but) I said 'I'm getting it from the Government. You take it ... Otherwise I'd have had to pay it from my own money.'*

Mrs Cox paid exactly her attendance allowance to the friend and lodger who cared for her while her husband was at work. The arrangement was practical and convenient to both parties, since the lodger had retired and was at home most of the day. Mrs Cox did not feel she was imposing on her carer ('I could not expect him to do it for nothing'); while he benefited from the £22 a week extra on top of his pension.

Whereas those paying for care provided by formal agencies had both been on income support, both of these informal payments were being made by disabled people who had some resources of their own, independent of the social security system. Mrs Paxton had a widow's pension from her husband's employer, and some income from savings or investments. Mr Cox had been able to retain his full-time employment while his lodger/friend took his turn at caring.

Moreover both the recipients of these payments had another income which enabled them to accept a non-economic rate for the job: Mrs Paxton's son supported his wife and may be considered to have been helping to finance the arrangement; the Cox's lodger had a pension of his own.

In both of these cases, therefore, it may have been the attendance allowance which was paid over, but it looks like the payment could not have been made if other resources had not been available.

Chapter 1 also identified some people with disabilities who purchased specific services in addition to their main source of care. There was one case involving payment to a formal organisation in an arrangement broadly similar to Mrs Wright's and Ms Darley's.

The mother of a mentally handicapped young woman spent £10 for her daughter to spend two nights a week in a short-stay hostel, so that she would be prepared for life in a residential home when her mother died.

Two elderly couples paid someone they already knew to help with the housework on a regular basis.

Mrs Bull paid her daughter £25 out of her £32.95 attendance allowance to help her caring husband with the domestic work shopping, cleaning, ironing and so on. The attendance allowance made this arrangement acceptable for both parties; as Mrs Bull said:

*It's good to have that money because you can get a little bit of help from your family like that ... All right, my*

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*daughter feels awful taking it, but it helps her in a way, and she helps me by doing it.*

Mr and Mrs Dartington gave a friend what they could – ‘no set amount’ – for a couple of hours help each week with the housework. There was no apparent connection with the attendance allowance or any other particular source of income.

Both of these informal arrangements had much in common with Mrs Paxton’s and Mrs Cox’s payments to kin and friend respectively. The money paid was not thought of in terms of pounds per hour in the way that would have been appropriate if a stranger had been hired. Both the Bulls and the Dartingtons had an occupational pension to take them above the basic welfare level; though neither couple was well off, this extra may have been just enough to allow them to release some income to pay their supporters. And both of the women who came in to help with the housework thought of their husbands as their principal source of income, and so could afford to provide help without thinking of it as a ‘job’.

Two other people were able to pay for non-standard forms of therapy to alleviate the physical problems associated with their disability.

Mr Goodwin purchased two mornings a week of physiotherapy in his own home. It cost £27 a week. In his view it was the attendance allowance (£32.95 a week) which allowed him to do this although he said that he probably could still have afforded the physiotherapy even without the allowance.

A disabled woman purchased a morning a week of yoga tuition in her own home, at a cost of £10 a week. However, as far as she and her husband were concerned, they simply made the £10 available from their weekly budget, without linking it specifically to the attendance allowance.

Mr Goodwin was used as the example of relative affluence earlier in this chapter, and in fact both of these disabled people had high incomes relative to others. Both thought of these services as ‘luxuries’ which they would have had to dispense with if they had been short of money for basics.

So, among the 29 attendance allowance claimants outside the Bexley scheme, nine turned out to be receiving regular personal services for which they made a weekly payment. Table 3 summarises their arrangements. Other people with disabilities, or their carers, had

**Table 3 Payments for care**

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**Primary care, formal services**

two did not have a kin carer; they paid formal services for the care which enabled them to remain in the community

**Primary care, informal relationships**

two paid their attendance allowance to the relative or a close friend who looked after them

**Support, formal services**

one paid for a weekly overnight stay in a hostel

**Support, informal relationships**

two paid a relative or friend who helped with the housework

**Therapy, formal services**

two paid for therapy to alleviate the physical problems associated with their disability

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paid for services on occasions to help with spring cleaning, to do decorating or other difficult tasks, or to provide cover when the main carer was away or needed a break. But it has not been possible to analyse these irregular transactions in relation to people's incomes.

None of the regular payments exceeded the amount of the claimant's attendance allowance, and several were explicitly based on that benefit. In some cases, the existence of a source of income with that name enabled the payment to be made without the embarrassment which would normally have been involved in money transactions between relatives or between friends.

Nearly one-third of the sample is, perhaps, more than might have expected to have been found paying for care. But most of the nine cases had two things in common which weaken the interpretations that the allowance was widely used for this purpose.

- None of the arrangements for providing household or personal care were seen by the participants to represent anything like a market contract between buyer and supplier. Only the two private therapy sessions were paid for on that basis: in all the other cases, there was a strong suggestion that the payment did not cover the full economic costs of the service, and a presumption that the care would have been provided anyway, with or without the payment. There is no sign of a market here.

- With the exception of the two people who made a contribution to the costs of care by altruistic organisations, all of who paid anything for personal services had an occupational pension or a wage which took their incomes above the level of basic social assistance plus attendance allowance. It can be suggested that it is the combination of attendance allowance plus independent income which allowed them to make this payment; if the allowance was added only to basic benefits, it could not be released from basic expenses.

### **Indirect payments for care**

Among the 29 members of the sample of 'ordinary' attendance allowance claimants, just over half reported that a relative had given up work, retired early or taken part-time work in order to be able to care for them.

Reduced or lost earnings represent an opportunity cost to the carer. We have not attempted to calculate these costs in terms of incomes foregone, but they could be substantial. At the extreme, they could consist of a full wage or salary of hundreds of pounds per week. Even those who were able to leave their employment on early retirement terms suffered a loss, which could last for the rest of their life:

The man who took early retirement at 52 in order to care for his wife was experiencing loss of earnings, partially compensated by his pension, during the period prior to the normal retirement age. He would continue to face a financial loss thereafter because of reduced pension entitlement: his years of service were less than they would have been if he had retired at 65, and his salary was lower than it would have been by the time he reached 65.

These financial costs were borne in the first instance by the carer him or herself, but they could often be shared. Some carers became entitled to social security benefits – the invalid care allowance or income support – when they gave up work, and the social security system may be considered to have met part of the financial costs of care in those instances. In other cases, the carer had previously contributed to a household budget which supported other members of his or her family; to the extent that their joint standard of living declined, the family would have shared the cost of caring. Thus the cost represented by reduced earnings could be spread about in quite

complicated ways, though the carers themselves were always among the heaviest losers.

In principle the disabled person could also contribute to this indirect cost of caring, to the extent that his or her income contributed to the standard of living enjoyed by the carer. Incomes were very commonly pooled, and administered by the carer, and it was not possible to pin the flows of income and expenditure down with any precision. In general it seemed that most transfers were in the opposite direction – that carers' income was being used to support the disabled person's expenditure, rather than the other way round. But it might be argued that any specific increase in the disabled person's income might reduce the costs incurred by the carer, and/or improve the whole family's joint standard of living. If so, that element of income could be seen as a contribution to the indirect costs of caring.

There were some indications that the attendance allowance may have had an effect on the supply of care which might suggest that it was an indirect form of payment.

- There were four kin carers who had chosen to work part-time rather than full-time so that they could continue their caring role. Three of them said explicitly that it was the attendance allowance which had made it financially possible for them to reduce their hours of work.

*That is where the attendance allowance comes in handy ... I really needed to work full-time. But that really wasn't ideal, not with Mum, because on a bad day, if I am at work, then Mum has got no choice but to stay in bed the whole day.*

- One man who cared for his disabled wife said that it was the attendance allowance (or, rather, the combination of the three benefits received by his wife, including attendance allowance) which had enabled him to retire early and care for his wife.

It was seen at the beginning of the chapter that some people thought of the attendance allowance as a form of contribution to the costs of caring kin. Although the direct evidence is not clear, it could be argued that this indirect form of paying for care might be as important as the more direct payments analysed in the preceding section.

## **References**

1. J. Martin and A. White, *The Financial Circumstances of Disabled Adults Living in Private Households*, HMSO, 1988.
2. P. Thompson, *Short Changed by Disability*, Disablement Income Group, 1990. The figure of £70 is for people in disability severity categories 9 and 10, excluding costs met by the Independent Living Fund.